

# CHANGING THE DEBATE ABOUT HEALTH RESEARCH FOR DEVELOPMENT

International  
Health Research  
Awards



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Changing the Debate  
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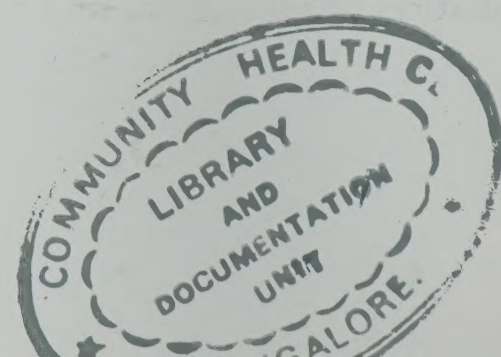
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# Changing the Debate about Health Research for Development

## EXECUTIVE SUMMARY

We represent ten groups of citizens and researchers from low- and middle-income countries who were recipients of International Health Research Awards (IHRA) presented at the Bangkok Conference on International Health Research for Development, 2000. The IHRA, funded by the Rockefeller Foundation and administered by the World Health Organization, recognized the need for us to find effective ways of solving our countries' health problems and acknowledged the special environmental constraints we face in conducting research and exploiting the results. We used this funding to explore alternative ways for harnessing largely untapped resources in our countries to generate and apply knowledge to improve people's health and address inequalities. In the Bangkok Declaration, we joined many others to express our commitment to research as a vital force for health of all of our people.

Six of our ten projects explored, for particular themes or health topics, ways of extending the benefits of research to special groups or populations. Four more proposed specific approaches to consolidate national research policy and systems for allocating public research funds and managing research.

From our collective reflection about what we have learned, we note ways in which our experiences represent change, particularly expansion of the traditional boundaries of research:

- broadening the research agenda by adding new topics, more voices and more perspectives than has been the norm in our settings
- expanding capacity to design and conduct research by preparing new groups of researchers to pose questions, design and carry out studies, and by engaging more partners and disciplines in addressing national priorities
- extending dissemination of research results, especially by using websites and mass media to reach decision makers and broader segments of the public
- encouraging uptake of research for policy and practice.

We want research to improve the health of our societies' most disadvantaged groups and to engage them in the process. Our work benefited immeasurably from networks and other forms of collaboration that our grants helped to support—and supported to an extent that was unusual compared to other forms of research funding. We linked our national and regional collaborations to global efforts, but endeavored to do so without being driven or preempted by the latter.

We are optimistic about the value of our experiences, but remain acutely aware of the unfinished agenda—an agenda that we incorporate into A CHALLENGE and A CALL for future action. We challenge ourselves, and others, to evaluate the effectiveness of our approaches to research for improving health systems and population health. We call on policy makers to adopt an evidence-based approach and to ensure that health systems are equipped to use rigorous research methods to embrace and analyze information from all participants. We close by asking donors and other international agencies for more flexible support so that we can benefit from global collaboration while maintaining our own priorities and building national and regional infrastructures to implement and evaluate new ways of doing research.







## Introduction



We are a group of citizens and researchers from low- and middle-income countries representing ten groups—academics, community groups, consumers, grassroots organizers, governmental and non-governmental organizations, and decision makers—who were recipients of the International Health Research Awards presented at the Bangkok Conference on International Health Research for Development, 2000. We, and many colleagues around the world, comprise a growing number of constituencies committed to assuring that health research be a vital force for improving the health of our people. All of us who were able to attend the conference in 2000 articulated this through the Bangkok Declaration (1).

Over the last four years, we have completed our projects and come together to compare our diverse experiences and approaches. We do not enjoy favorable conditions for doing research, but do conduct our activities where the world's greatest challenges to health exist. We must work as effectively and efficiently as possible in our settings—and in collaborations most conducive to addressing those conditions. Our interest is in working collectively to build and sustain highly productive systems of research within our countries, to combine resources effectively within our regions to fill gaps in knowledge for improving health, and to link national and regional collaborations more effectively to global efforts—without being driven or preempted by these.<sup>1</sup>

We see mounting global commitment to narrowing the gap in health, wealth and well-being between the world's most disadvantaged and advantaged populations. Individual United Nations agencies have signaled a new level of dedication to reducing poverty and increasing equity (2). They articulated this collectively in the United Nations Millennium Declaration 2000 (3) as Millennium Development Goals (MDGs). In growing recognition that, especially in lower income countries, health gains can hasten economic growth (4,5), the MDG strategy integrates improvement of population health with poverty alleviation, human, and economic development. Greater acknowledgment in our countries, and in the international community, of the crucial role of health in development creates a new urgency for more effective approaches to advance population health.

Laudable efforts, especially during the last 15 years, create a basis for the work ahead, but they are not sufficient.<sup>2</sup> The Commission on Health Research for Development (6) and the Global Forum for Health Research have each drawn attention to a gross misallocation of research investment that favors the world's most affluent populations. The latter characterized it as the "10/90 gap" (13). Our research experiences indicate that the link between research investments and improved health is more complex than imbalances in funding of research pertinent to the major causes of illness and disability.

Many of our nations' leaders see health research as a waste of resources, rather than as an

1. This paper was conceived when representatives of each project met in Arusha, Tanzania, in November 2002. We met again in Annecy, France, in March 2004 to shape the paper as a collective reflection of our experiences and the lessons learned.

2. The last 15 years produced: a landmark report on health research for development (1990) (6); analysis of how to address the very significant gaps in knowledge, and its exploitation for reducing the burden of ill health for the majority of the world's people (1996) (7); creation of the Council for Health Research for Development (1997) (8), the Global Forum for Health Research (1998) (9), WHO's Division of Research Policy (1999) (10), and the Alliance for Health Systems and Policy Research (1999) (11); to facilitate the drawing together of researchers from a wide range of fields—and to link them to potential sources of international funding from science and development agencies, foundations, and others. WHO's 1999 World Health Report proffered evidence about how much research and knowledge have contributed to health. (12)



irreplaceable, strategic element of health and development. Observation of how research is done in many industrial countries may have led them to conclude, in the face of pressing needs, that greater support for research within our countries would amount to costly indulgence of researchers. We believe that our circumstances require a research approach that is sufficiently inclusive, coordinated, and flexible to enable us to respond to local priorities and urgent challenges.

The old ways have not been conducive to building public understanding of, engagement in, and support for research. They have been insufficient for encouraging a popular culture of inquiry and a research system oriented to identifying and solving problems—based on support of policy makers and citizens who expect new knowledge and its use to improve society and their well-being. We want to move away from “ivory tower” research, demystify the process and transform it into an empowering one for making health policy, and planning and administering health care programs. And we want research not only to benefit the health of our societies’ most disadvantaged groups (disabled, indigenous groups, women and others), but also to engage them in the process.

The flexibility of the three-year International Health Research Awards, funded by the Rockefeller Foundation and administered by the World Health Organization, provided an unusual opportunity to strengthen the way research is done. The “spirit” of the IHRA incorporated a critique of the usual ways of doing things and encouraged change (14), specifically:

- from stand-alone pursuits to creative multi-disciplinary partnerships involving multiple stakeholders, especially local communities and policy makers;
- from one-off, self-contained and short-term projects to longer-term initiatives linked to ongoing activities and institutional policies/infrastructure to ensure sustainability;
- from research for its own sake to a focus on national health priorities; in-built monitoring and evaluation; dissemination among all key stakeholders;
- from building individual researcher’s capacity and/or individual institutions in isolation, towards synergistically strengthening teams of researchers and host institutions in the context of the broader health system; and
- from North to South priority setting to Southern focus and South-South partnerships.

Noting “urgent need for some bold and imaginative thinking about novel initiatives to increase the productivity of health research for development,” the IHRA request for proposals attracted 542 submissions. Our ten projects are a mere subset of a much larger number of projects where, even without IHRA grants, colleagues are exploring ways to assure that research contributes more and more quickly to solving enormous health problems burdening our populations.

We offer the following highlights of our work<sup>3</sup> to invite colleagues around the world to share what they are doing, and to stimulate debate with policy makers about alternative ways of harnessing largely untapped resources in our countries in order to generate and apply knowledge to improve people’s health and address inequalities.

3. Please refer to <http://www.who.int/rpc/summit/en/> for more detailed documentation on each project.



## Our Projects: The International Health Research Awards (IHRA)

**T**HE awards recognized the need for us to find effective ways of solving our own countries' health problems—and to confront the particular environmental challenges we face in conducting research and exploiting the results. Six of our ten projects explored particular themes or topics, or ways of extending the benefits of research to defined groups or populations. Three of these engaged in collaborative, multi-site activities across large countries. The other three projects operated similarly, but across regions. Four more proposed to consolidate national research policy and systems for allocating public research funds and managing research.

### EXPANDING THE BOUNDARIES OF RESEARCH

*Brazil: Consumer Research and Action for Health.* In Brazil, our project organized community surveillance of local health systems, and provoked a new level of attention to remediable deficits in primary care from consumer organizations, citizens, professionals, media outlets and politicians. We studied drug shortages in community clinics; marketing of unsafe drugs, and rational use of all pharmaceuticals; disparities in private versus public primary care services (contrasting experience of low-income women using public and private clinics for cervical cancer screening); irregularities in private health insurance contracts; and a predisposition of those dependent upon free or low cost services to accept whatever quality and conditions existed without insisting on standards of care mandated by post-dictatorship Brazilian law. We completed the research-to-policy process by turning our findings into municipal policy and practice using methods developed with support from our International Health Research Awards.

*India: Strengthening of Health Research in Non-governmental Organizations.* Our project supplemented India's health research community and challenged its boundaries in order to improve services and health, often in remote areas far beyond the reach of traditional programs of research. We built new capacity within community-based organizations to assess community needs, evaluate their programs of health services, and improve care for some of India's least served populations. Our team compiled the nation's first inventory of the 517 community-based organizations providing health services. They assist populations whose rates of infant and maternal mortality have been highest, and life expectancy shortest. We invited 208 of these organizations to an initial workshop. With a specially prepared manual, "User Friendly Survey Research and Statistics for Health Workers: A Primer" in hand, 57 organizations collected data in the field, and in local dialects. Forty-nine organizations formulated detailed research proposals and data collection tools. Most addressed reproductive health, maternal health, child health, and nutrition. Ten dealt with communicable diseases, such as malaria, tuberculosis and leprosy and others focused on HIV/AIDS, other STDs and tobacco use. Each participating group prepared simple tables for analysis and 36 groups completed full papers—including action plans based on their research.

*South Africa: The South African Gender-based Violence and Health Initiative (SAGBVHI).* South Africa has the highest reported rate of rape in the world (230/100,000 women). In its strategic plan (1999–2004) the National Department of Health recognized that the health sector has an important role in addressing gender-based violence. However, policy makers, researchers and gender-violence activists shared concern that the health sector was not equipped



to respond adequately to abused women in health facilities, and to collect medico-legal evidence. There was a need for development of a research agenda for gender-based violence bringing together stakeholders and researchers so that key priorities were addressed and the potential for research to result in policy was maximized. We identified research priorities and undertook a situation analysis of public health facilities in all provinces to determine what services were being offered to women after sexual assault. We also began working with the National Department of Health on a sexual assault policy and clinical management guidelines. The findings from the situation analysis informed the debate about what service model would work best under the resource constraints. Our prioritization of areas for research led to several collaborative projects. We awarded two small grants and held two annual conferences to bring together researchers and program people as part of the capacity development.

*African region: Strengthening midwives' research capacity in ten African countries through the Africa Midwives Research Network (AMRN).* Midwives from five countries created this Network in 1992 to share scientific information and improve midwifery practice and education throughout the region. As schedules are unpredictable, the hours of work often intense and very long, most of our region's midwives have had no opportunity to develop skills for conducting research, or even for using research findings in their practice. The HIV/AIDS epidemic has compounded an already complex array of challenges—in settings where resources are as scarce, or more scarce, than anywhere in the world. Thus, AMRN started offering research courses and creating opportunities for midwives to share research findings. Our IHRA project enabled expansion into eight more countries where we offered courses on research methods, shared scientific literature and findings from our own studies.<sup>4</sup> The Tanzania-based regional Network office managed our project through contacts with nursing and midwife associations and university departments. We asked local partners to identify priority areas for research, mentors, and potential trainees—and to initiate national research networks. Inadequacies in email, fax, and telephone facilities hampered contact and made communication our foremost challenge. Even so, using the IHRA grant, we gathered 16 nurse-midwives from eight countries for training in problem identification, using the internet to access and search the literature on research methods, proposal development, data collection and analysis, scientific report writing and presentation. Home-country mentors supervised completion of preliminary proposals and data collection, and helped new trainees with their first research reports. Twelve completed full research papers.

*Asia-Pacific Region: The Asia-Pacific National Health Accounts Network (APNHAN) and Comparative Study of Equity of Health Systems Finance and Expenditures.* The Asia-Pacific National Health Accounts Network (APNHAN) emerged in 1997 from the spontaneous coming together of seven National Health Accounts groups at the WHO 50th Anniversary Celebration Meeting in Bangkok.<sup>5</sup> We operate a peer-to-peer network of national counterparts in both developed countries (e.g. Australia, Korea, Japan) and developing countries (e.g. Mongolia, Sri Lanka, Thailand). Members collaborate and assist other members in the same region on technical matters, without mediation by North-based partners. The IHRA grant in 2000 provided the network's first funding. We used it for several projects concerning uniformity of technical standards for international reporting of National Health Account statistics and the development of methods to extend National Health Accounts systems to analysis of distributional,

4. Participating countries include Tanzania, Zimbabwe, Zambia, Eritrea, Kenya, Uganda, Mozambique, Egypt, Djibouti, Nigeria, Ethiopia, Swaziland, Botswana, Namibia and Malawi.

5. This network was originally formed under the umbrella of the Asia-Pacific Health Economics Network (APHEN). APNHAN retains the affiliation, but operates largely independently.



or equity issues, in financing and expenditures. At the time, national estimates could not be relied upon for comparative studies.

*Latin America and Caribbean Region: Improving the links between reproductive health and health sector reforms (VINREPLAC).* We initiated a novel program of research on reproductive health and health sector reforms. To encourage more empirical studies with practical consequences for design and implementation of policy, we organized a region-wide, small grants competition. We requested that each grant applicant structure into the research proposal an explicit role for national policy makers. Experts in reproductive health and health sector reforms from different countries evaluated the proposals and identified five for funding. In Bolivia investigators assessed an innovative strategy to reduce women's morbidity and mortality by offering conventional sexual and reproductive health training programs in settings where women could gain some economic independence (through making carpets and clothing), so they could be generating income and confidence as they learned. One group of Colombian researchers identified barriers to family planning programs for women whose care was subsidized by the social insurance scheme created by the reform; another explored the needs of women who had no health insurance. Our Peruvian counterparts studied a new way of managing care for women and adolescents in which communities shared this responsibility with health authorities. Uruguayans organized the broadest project—to evaluate obstacles to implementation of a new model of sexual and reproductive services that arose from health care reform.

#### CONSOLIDATING SYSTEMS

*Republic of Georgia: Health Research for a Responsive Health Care System.* Our project in Georgia promoted a national consensus process for redirecting research policy to meet national health needs. We instituted a transparent process for distribution of research funding to overcome lack of collaboration among research institutions, and started to rebuild human and institutional research capacity in the wake of the most devastating economic crisis in any of the republics emerging from the dissolution of the Soviet socialist system. Between 1990 and 1995, Gross Domestic Product fell by 78%, heightening the need for a well-functioning health system in which research contributed to its reform and renewal. From 1998–2000 approximately \$1,366,871 US financed research in 50 national institutions with research staff of 1,427 individuals—a drastic reduction from previous levels. Our project immediately established a broadly representative governing body to oversee the process leading to a National Health Research Agenda. The International Health Research Award served as a tool for engaging sufficiently wide participation to assure legitimacy in the eyes of all interested parties.

*Nepal: Capability strengthening of health research network in Nepal—focus on national and institutional review capacity.* With the establishment of the Nepal Health Research Council (NHRC) by an Act of Parliament in 1991, this country gained its first national institution to promote and supervise health research activities. When we at NHRC applied for IHRA funding, Nepal had no health research policy guidelines, and afforded little opportunity to discuss or promote equity as a primary value within research. Our challenges to improving productivity of research were enormous: too few researchers with methodological training or experience in managing research to constitute a critical mass; very limited access to international health literature; absence of incentives to do research or structures to promote research careers. These deficiencies were aggravated by brain drain, frequent changes of scientists in key positions, little appreciation of the potential of research within the Nepalese population or among policy makers, and minimal support from the government. NHRC's priorities for use of IHRA funds



included preparation of policy guidelines, establishing a health research information research center, creating a core research support team, and promoting a continuing dialogue among previously isolated researchers and institutions.

*Tanzania: Strengthening the Tanzania National Health Research Forum (TANHER), a National Mechanism for Better Health Research Coordination.* As Tanzanian scientists are painfully aware, fragmented, uncoordinated, and low-quality research that is not dedicated to priority national health problems wastes scarce resources—and opportunities to solve enormous problems. We formed the Tanzania National Health Research Forum in 1999, before we applied for the IHRA grant, and designed it to be an inclusive entity for bringing together researchers, policy makers, non-governmental organizations and community groups to assure efficient use of our resources to reduce the staggering burden of disease in Tanzania. Infant mortality is 150/1000 live births, maternal mortality 600/100,000. Malaria, the number one health problem, kills 274 Tanzanians each day. Diarrheal diseases, HIV/AIDS, tuberculosis, malnutrition and schistosomiasis are other major causes of morbidity and mortality. Our International Health Research Award reinforced several aspects of our Forum, including coordination of research, establishment of standards and guidelines for review and clearance of proposals, capacity strengthening through training and networking, and promoting use of health research results.

*Thailand: The Alliance and Research Coordination Network for Evidence-based Health System Reform.* We formulated a project of wide scope and complexity in which a new approach to research within Thailand formed the basis for proposing a massive and visionary reform of the health system. This process led to a proposal for a National Health Act that is now before the Prime Minister and his cabinet, awaiting further action. Within the draft Act lies a road map for ongoing health system reform, including networks for health policy and system research to bring community activists into the health system reform movement. Our process involved citizens from all over the country, non-governmental organizations, researchers, health professionals, government officials from health and other sectors, legislators, print journalists, radio and television producers, and many others. Specially designated committees commissioned research and assigned tasks to research groups within Thailand to prepare, for each element of health reform: governance, health promotion, hazard control, health services, research, health information, consumer empowerment, and health workforce. We also compared Thailand to a selected set of countries in the region. Our IHRA funds constituted a tiny proportion of the research funds, but were disproportionately important. Restrictions on other funds prohibited supporting the important contributions of community activists. Nor had the usual sources of research funding in Thailand previously supported clinical, multi-site studies.



## Opening Up Research

**T**OGETHER our projects push the boundaries of traditional concepts of research by including more topics, participants, perspectives, disciplines, methods, means of dissemination, and advocacy for use of the results in policy and practice, than has been the norm in our settings. Because research will not contribute to better health outcomes if results are not applied to policy and practice, we value every one of these activities as essential elements of a continuous cycle of research from shaping of questions through use of results in policy, programs, and practice—and generation of new questions.

### BROADENING THE RESEARCH AGENDA

In South Africa, our goal was for gender-based violence to be recognized as a *new priority on the national health research agenda*. Prior to the activities inspired by the South African Gender-based Violence and Health Initiative, and supported by an IHRA grant, only a small number of South Africans concentrated on research, advocacy or training at the intersection of gender-based violence and health. This initiative facilitated the interaction between researchers and practitioners. By bringing together the full range of interested parties, our Initiative hugely strengthened the focus given to this neglected health crisis as it gained a place on the national research agenda.

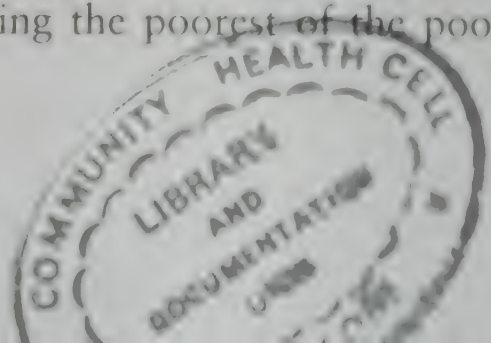
In Latin America and the Caribbean, we drew *new attention to an area of research we believed to be significant and neglected*. The Mexican Foundation for Health (Funsalud), and the Population Council's Latin America office, built our project on the observation that health sector reforms seemed to impinge on reproductive health services for women in significant, but somewhat different, ways in each setting. As no one understood the nature of, or consequences for reproductive health, we designed our grant competition to encourage investigation of the interactions between the two. By distributing a request for proposals among more than 200 researchers across the region, we attracted more investigators to concentrate on the needs of poor women who rely on services that were modified by the reforms.

In Brazil, where consumers of health services complained about the scope and quality of primary care, we *introduced new voices and more perspectives in shaping research* questions to understand the problems and begin to solve them. Questions consumers raised guided a multi-site, multi-disciplinary program of research. Health and legal professionals from Brazil's Institute for Defense of Consumers (Instituto Brasileiro de Defesa do Consumidor, IDEC) organized our project with researchers from the University of Brasília and partner entities from the National Forum of Non-Governmental Consumer Organizations.

### EXPANDING CAPACITY TO DESIGN AND CONDUCT RESEARCH

In Georgia, South Africa, and Tanzania, we *encouraged researchers to address national priorities* by designing competitive small grant programs, especially to draw the attention of young talent. As well as conducting studies, by participating in these programs on national priorities, these investigators learned how to design studies that are well suited to the health needs and health systems we are trying to improve. In Tanzania we also *assisted African scientists to prepare for international research funding competitions*. We organized special workshops, reinforced by longer-term academic programs, to assure that each participant completed a fundable project proposal to submit in competitions. Additional support from the European Union allowed us to test this new model for developing research on malaria—our number one killer.

In India, working with community-based organizations serving the poorest of the poor—





tribal populations in remote areas, landless laborers in rural areas, and slum populations in cities—we enabled them as a *new group of researchers to design and carry out program evaluation*. Tata Institute of Social Sciences, working with four partner institutions (one academic institution and three large non-governmental organizations in the field of health), organized India's first experiment in training front-line health service providers to use epidemiological and social science research to assess the impact of their programs.

In ten countries across Africa, where it is common for mothers to die giving birth, we *encouraged and supported nurse-midwives to pose their own research questions, and to design and conduct studies* to reduce risks associated with childbirth. We provided a regional training and support community to enable these key but isolated health professionals to inform interventions to increase access to reproductive health services and improve outcomes for poor women.

In Brazil, we *engaged users of primary health care centers in research*. Consumers' repeated complaints that basic medications<sup>6</sup> for controlling common conditions and avoiding unnecessary hospitalizations were unavailable at these centers prompted one facet of our project. Brazil's national health legislation mandated availability of "essential drugs" in all public primary health care facilities of the Brazilian Unified Health System, so we prepared a questionnaire that included an easy-to-use checklist of drugs intended for routine use in ambulatory care. Local citizens, including those who did not have the benefit of education beyond primary school, used this instrument in 50 health centers located in 11 cities across Brazil's five regions between March and September 2002 to confirm the presence or absence of these products. The data supported conclusions about whether local health facilities were well, moderately or poorly stocked with the "essential drugs" required under Brazil's national health legislation.

In all of our projects, we *engaged many partners and disciplines* to increase the relevance of research to improving policy and health programs. In Georgia, to address issues prominent on our newly formulated agenda of national research priorities, we introduced new disciplines and multi-disciplinary collaborations so that research could inform operational aspects of our health system. This entailed a move away from the "old style" of purely clinical research. In Brazil, Latin America, South Africa, and Thailand our projects also drew together researchers from several disciplines to combine their perspectives and methods to solve pressing problems. In Uruguay, based on fruitful collaboration among epidemiological and social science researchers, the host research institution stepped beyond its usual academic sphere of influence to become a very visible leader in national policy on sexual and reproductive health. These examples are likely to encourage others in traditionally insular disciplines to collaborate in seeking multidisciplinary solutions to pressing problems.

Based on wide consultation, *we revised national ethical guidance for research to encourage greater consideration at the stage when scientists first develop proposals*. In Nepal, an early chairman of the National Research Council drafted Nepal's first ethical guidelines, following international principles, but the guidance was not well understood. Although no cases emerged in which research conducted in Nepal was known to have violated any ethical principle, occasional criticism of the council erupted on the approval of controversial studies.<sup>7</sup> Representatives of Nepalese research organizations, review committee members, legal experts and ethicists from

6. Most frequently out of stock: levothyroxine, essential for hypothyroidism, and permethrine for lice, both missing from all centers in 9 of 11 cities. Ibuprofen, an essential non-steroidal anti-inflammatory drug was absent in all centers in 8 cities. Asthma is one of the most common causes for hospitalization of children in Brazil, yet theophylline syrup was out of stock in the centers of seven cities. While diabetes is a major public health problem in Brazil, regular pork insulin was also completely absent in Centers of five cities, regular human insulin in three cities, and metformin in four cities. Central nervous system drugs, even those which do not cause dependence, are subject to special controls in Brazil, and many of these drugs were less accessible, such as sodium valproate and lithium, absent in 4 cities, or haloperidol, absent in 2 cities.

7. For example, controversy surrounded the approval of study for vitamin A supplementation in antenatal period and a trial for Hepatitis E vaccine in an urban community that needed special provision for review and change in the study site.



abroad, and members of the ethical committees of the neighboring countries then participated in a consultative meeting and adapted the guidelines for local use.

Nepalese scientists continue to raise fundamental questions as they work with the new guidelines. Are there universal ethics that can be applied to all cultures and contexts? How is it possible to apply ethical guidelines, even those drafted by and for Nepal, when concepts of beneficence, justice and risk benefit analysis do not remain very clear in many situations? To what extent may the ethical review process slow attempts to bridge the 10/90 gap? Of what use are the guidelines if their implementation is not ensured? An unprecedented level of consultation on guidelines enhanced ownership of them by our scientific community, even as it provoked questions. We hope the questions raised in Nepal will encourage our peers in other countries to articulate their questions in ways that will support capacity development. Collectively our questions and consideration can inform global debates about the suitability of international guidance.

#### EXTENDING DISSEMINATION OF RESEARCH RESULTS

We relied on *many forms and forums for dissemination* in order to increase the productivity and application of our research — and to bring our findings to the attention of those who could use and benefit from them. *Websites, conferences, and mass media* have proven to be particularly powerful instruments. In Brazil, extensive mass media coverage broadened awareness of common problems in its health system and promoted widespread ownership of the citizens' campaign to address them. For example, once we assembled initial study results on drug shortages, the popular media reinforced consumer insistence that municipalities supply “essential drugs” in every primary care center. A variety of community and national organizations then assumed roles as “watchdogs,” informing municipal health councils of their findings and continuing to monitor and bring enforcement actions based on methods our partners developed and posted on the open, IDEC website. In Africa, conferences were sometimes the best means of sharing information among researchers (AMRN) or between researchers and others to build nascent collaborations (South Africa).


#### INCORPORATING EVALUATION

Although we see evaluation as an integral part of the research process, the relatively short three-year time span of IHRA funding did not allow us to complete many project evaluations, especially of elements that we believe to be of the utmost importance: *uptake and impact* of the work. We made a start and can anticipate how important assessments of future projects will be. In India, we did thoroughly evaluate the training program itself, but did not have enough time or funding to evaluate the extent to which our trainees applied their findings to improving the field programs. We learned that participants felt quite confident using the skills of problem formulation, data collection and report writing but had greater difficulty with two technical research skills—design and data processing. More than two-thirds of the participants concluded that they could now undertake survey-based research studies on their own with minimal guidance.

Before selecting any trainees, we evaluated the research experience of the 208 Indian community-based organizations interested in participating. These data showed that 65 percent of them had no previous research experience, and of the 35 percent that had undertaken research, 70 percent had never used their findings to shape their programs. Most had conducted baseline surveys or evaluation studies to fulfill the requirements of the donors. Donors may have gleaned data for their own purposes, perhaps to justify particular types of funding, and assisted these community-based organizations in other ways. There is, however, little evidence that these donor-driven studies contributed to research capacity for health. This finding made us particularly eager to follow up to determine whether and how the study findings in our project have been used, or whether the training was exploited after the workshop. We would like to compare the impact of our approach to inspiring local health organizations to do research to that of the donors, and use the results to improve health programs.



## Encouraging Uptake of Research for Policy and Practice

N many of our projects we made special efforts to *promote uptake of research findings in policy and practice*. The examples from South Africa, Thailand, Uruguay and Tanzania illustrate benefits of planning research with the intention of influencing policy or practice, and of researchers engaging with policy makers in ways that inform design of the studies. Even without more extensive evaluation it is apparent that some of our findings have already contributed to advancing policy and practice; others are poised to do so.

### SPECIFIC EXAMPLES OF UPTAKE

In South Africa, having aligned a forceful coalition with an increasingly visible set of messages for shaping policy and practice, we forged a strong relationship with the National Department of Health and exerted considerable influence over key aspects of policy development. Members of our group drafted much of the National Sexual Assault Policy and Clinical Management Guidelines, incorporating comments from the consultative processes. SAGBVHI members played a particularly active role in the new, national policy on post-exposure prophylaxis to prevent the transmission of HIV to sexual assault survivors.

In Thailand, the award has supported the creation of the Clinical Research Collaborative Network, a consortium of medical schools with skills in clinical research. International evidence supports use of cholesterol-lowering drugs as an effective strategy to reduce cardiovascular disease and associated deaths. But an unpublished meta-analysis of Thai cardiovascular disease risk factors studies showed that total cholesterol was not a predictor of cardiovascular disease death in populations where the average mean cholesterol was low compared to Western populations. The Network is ready to coordinate the multi-center study required to decide whether or not national investment in cholesterol-lowering drugs will be beneficial. As these medications are relatively expensive, it is an important decision for the Thai health system.

In Uruguay, health centers had historically limited their scope to maternal and child health; they began to add family planning only during the 1990s. Starting in 2001, the Ministry of Health promoted the implementation of a new approach called the “Women’s Integrated Health Program” (“SIM”) to attend to women’s needs beyond their pregnancies and roles as mothers. Primary health care centers were not well prepared to do so when implementation of SIM began in the capital’s primary care units, serving approximately 123,000 women. SIM reflected widespread desire for recognition of women’s health needs beyond those related to pregnancy and motherhood. It incorporated family planning, prevention of cervical cancer, and prevention of sexually transmitted diseases. However, researchers identified deep tensions in the transition between the old and the new SIM model that were reflected in systematic misunderstandings by personnel of the new program’s philosophy. Thus, researchers decided to use their findings to lobby in favor of stricter application of SIM regulations as a way to better protect women’s reproductive rights. One impact of the research was addition—for the first time—of emergency contraception to services provided low-income women at their local health centers.

In Tanzania, studies supported by the IHRA about drug resistance to widely used anti-malarials contributed to the change of national policy for malaria treatment. The new evidence convinced Tanzanian health authorities to replace chloroquine with sulfadoxine pyrimethamine derivatives.



MECHANISMS FOR INSTITUTIONALIZING  
THE LINK BETWEEN RESEARCH AND ITS USE

Three projects designed to consolidate systems of health research and to link them with health systems have taken *steps to institutionalize the "research to policy" process*. In each case the design of research and of the national programs of research reflect the intention to systematically improve health systems.


Tanzania's Ministry of Health has *created a mechanism to institutionalize the link between research and policy*. First it requested Tanzania's National Health Research Forum and National Institute for Medical Research (NIMR) to assess the overall capacity of the Ministry to analyze and apply research results to policy and decision making. Once the assessment revealed that there was no clear receptor of research results in its structure, the Ministry of Health commissioned NIMR to develop a new unit, the National Health Research Information Centre, to capture health research information, analyze and translate it into simple and clear policy language for policy and decision making processes.

In Georgia, where the Curatio Institute coordinated the consensus development process as part of renewal and consolidation of a post-crisis research system, uptake of results was an explicit component of the project's agenda from the start. The Institute promoted advocacy to ensure that all recommendations developed through publicly funded research responding to priorities of Georgia's health system would be absorbed in public policy and implemented on the national level. As a new entity, the National Health Research Council, will assume the coordinating role, played initially by the Curatio Institute, this set of responsibilities will be institutionalized in the new body.

In Thailand, because translation of research results into practice lies at the center of health system reform, the Ministry of Public Health asked our project's lead organization, the Health Systems Research Institute, to assume a new role as the ministerial unit for research and innovation, to coordinate research among Ministry departments and to consolidate the results for use in government health programs and research policy. From the start of Thailand's process of health system reform, we designed research through collaboration among researchers, stakeholders and policy makers. We intend the new health system, as proposed in the draft National Health Act, to integrate the input of citizens with that of researchers and policy makers.



## Networks and Collaboration

F our systems of research perform as we would like, they will link more people and resources across countries and regions to intensify synergy between local and global knowledge. Importantly, the IHRA program emphasized the role of collaboration and encouraged us to concentrate on networks, whether structured as national or regional projects. In addition to our efforts, in several projects, to unify national systems of research, our *networks everywhere provided the best, and sometimes only means for consolidating our gains and institutionalizing collaboration.*

### INSTITUTIONAL NETWORKING

In Thailand, multi-center collaboration will be needed repeatedly to answer questions for the Thai health system—about generic drugs, locally available new treatments, herbal medicine and other alternative treatments. The Clinical Research Collaborative Network, supported by the award, has transformed research relationships between medical schools from a culture of competition to one of collaboration. This is resulting in a spirit of mutual learning and more effective and productive clinical research. Six more networks operate to inform development of “healthy public policy” in the areas of industry and energy; agriculture and rural development; transportation and urban development; water resource management; international trade; and natural resource management.

In India, our project website allowed formation of the “Community-Based Organization Health Research Network” to link 208 organizations in a system providing information and mutual support. A website-based network newsletter circulates to keep all members informed about action research. Only these network activities maintain the connections among these isolated entities to encourage them to continue to study their own programs and to improve them.

In Nepal, the process of applying for the award and undertaking the project enticed isolated institutions to work together. Other calls for proposals for specific pieces of research often result in one institution competing with another and a degree of secrecy. This traditional approach may help some institutions and individuals to produce good scientific studies but often with limited relevance to their countries’ specific problems. It is difficult to say whether the IHRA networking will continue after this project but we expect that the experience of working together will help the institutions involved to maximize their combined effectiveness in addressing the research needs of the country. IHRA efforts to promote networking comprised an attempt to maximize resources and avoid duplication and wider sharing of information among the researchers within the country and within a particular field of research.

The African Midwives Research Network is pioneering in that it is the only mechanism offering opportunities for midwives across the African continent to turn field experience into shared agendas for research to improve reproductive health. Maintaining communication for research training, multi-site collaboration, and convening scientific conferences has been enhanced through growth and maintenance of this network.

All of our projects benefited immeasurably from networks and other forms of collaboration that our grants permitted us to support—including communications and travel to maintain contact—to a degree that exceeded what most other sources of research funding have covered. This unusual degree of flexibility in how we were able to spend our IHRA grants is part of what made this funding more effective for building collaboration initially, and for sustaining newly gained



improvements in capacity over time. This has been true in Brazil and across APHAN's Asia-Pacific partners as well as in Africa where AMRN faced the gravest challenges in communication. However, as our IHRA funding runs out, it will be difficult to replace these resources, precisely because other funding tends to be more restrictive.

#### ATTAINING REGIONAL AND INTERNATIONAL SYNTHESIS

Our Asia-Pacific National Health Accounts Network provided a voice and profile for south-based groups to achieve status as partners in dialogue with the Organization of Economic Cooperation and Development (OECD) on the System of Health Accounts standard. In order to shape a uniform system of reporting suitable to the Asia-Pacific region, our Network operated as a focal point for discussion with the OECD Secretariat. Funding from the IHRA grant allowed APNHAN members, who otherwise would never have been at the table, to attend OECD consultations in person. At least partly because of contributions from our Network, the System of Health Accounts (SHA) draft that emerged from OECD better suited our needs for comparative research than it would have without our input—and for capacity strengthening in each of our countries. Having arrived at the meeting without support from OECD or other interested parties, our additions to the discussion could be truly independent.

Our experience demonstrated that existence of a common reporting standard encourages generation of comparable data and, more importantly, public reporting of these data. Although comparison is largely descriptive in method, it has major impact on overall policy making, as is apparent from OECD experience among industrial countries. Prior to reaching agreement on a new version of OECD's SHA, it was easier for Bangladesh to compare its expenditure profile with the USA than with Thailand. The first two countries in the world to publish SHA-based estimates were APNHAN members (Korea, Sri Lanka). Then many other regional partners soon adopted the OECD System of Health Accounts to bring the Asia-Pacific region to the forefront of global adoption. Equitap (our largest project funded by the EU grew out of our IHRA experience and start-up funding) represents a major scientific event in the field of comparative health research in the Asia-Pacific region. We are now able to compare 15 countries using the SHA as a common ruler to define and measure expenditures from different financing sources, and their use by origin and function.<sup>8</sup> Final results will be published in late 2004. Each of our countries can now use the comparisons to strengthen its own health system.

Most equity work has focused on programs, special interventions reaching the poor, not on health systems. But Equitap results point to the overwhelming importance of systems on actual equity performance in countries. Outside Europe no one has ever used comparable methods for analyzing a regional cross section of countries. The countries we are comparing span a much wider diversity. They vary from some of the poorest countries in the world (Nepal, Bangladesh) to some of the richest (Japan, Hong Kong SAR), and their economic systems range from that of China and India to that of Hong Kong and Taiwan, with health systems ranging from the social insurance systems of Mongolia and Korea to the mostly privately-funded health care systems of India and Bangladesh. Our findings indicate that it is health system design that matters most for equity, not specific program design or innovation. System configurations that work best for equity at the upper end of national income range also provide more equity at the lower end. That is, overall system design (how people in a country pay for health care, and what rules systems apply with respect to accessibility—e.g. universal access versus that targeted only to

8. This feeds into the microanalysis by providing the macroweights. Equitap looks at the distributional performance of each financing mechanism separately. However, to obtain an overall system assessment, one needs to add the assessments for each mechanism, for which SHA numbers provide the weighting. That is, how much of the total expenditure in each country is out-of-pocket spending versus social insurance, or other forms of financing care.



improve access to care of the poor) matters more than having special targeted programs or exemptions to reach subgroups of the poor.

We expect our study to contribute to global debate about the effectiveness of various approaches to achieving equity, especially because our findings on system impact contradict today's tendency to create specific programs to reach the poor. Equitap will not help ministries design specific projects, but it does illuminate bigger issues as to why some countries achieve greater equity—sometimes a great deal more—than others.


#### ENCOURAGING AND RESTRAINING EXTERNAL PARTNERS

In Tanzania we developed a new way to encourage external research partners to contribute to priority research—and to constrain them from unethical or otherwise unwelcome research in the country or on its citizens. As one element of our project, Tanzania's National Health Research Forum took responsibility for clarifying policy and forging consensus on standards and guidelines for review and clearance of research proposals. One of our partners, the Medical Research Coordinating Committee at the National Institute of Medical Research, took a crucial step to *strengthen Tanzania's control over the terms of engagement with international collaborators*. As a consequence, proposals involving researchers or research funding from outside Tanzania must be cleared by the country's National Review Board before any fieldwork is undertaken.

For proposals involving only Tanzanian researchers, decentralized Institutional Review Boards are newly vested with authority to handle the review themselves, and send reports, not full proposals, on to the National Board. But local Boards do forward all proposals involving international parties, along with their comments on these, to the Medical Research Coordinating Committee for careful consideration. This leads to negotiations whereby the proposer may be asked to modify the proposal to meet Tanzanian needs and priorities—or to forego approval and withdraw from Tanzania. Scientific and ethical evaluations now proceed simultaneously, reducing the time investigators await results (from 9–14 weeks to 4–6 weeks). By delegating much of its previous workload to the institutions, Tanzania's national authority is able to concentrate its attention on proposals involving external collaborators.



## Reflections on Change

S we have reflected together, several themes characterize our experiences and convictions: orientation towards health and equity; the value of exploration, collaboration, inclusiveness, transparency, and unification of effort to foster vibrant systems of research, nationally and regionally. But we have not been able to carry out our work without resistance.

In Georgia, opposition emerged as we adopted national priorities. Researchers and institutions, concerned that they would lose advantage in the change from the earlier Soviet-era approach, challenged our new priorities as well as our new methods for evaluating research relevance. Data from 1998–2000, analyzed as our project began, revealed that two research institutions (4%) had divided among them more than 300,000 GEL per annum of the total public research funding compared to fewer than 50,000 GEL shared among 39 institutions (79%). The new transparent process for allocating funds and fair competition resulted in a dramatic redistribution of resources to those institutions and researchers who could contribute most to improving the health system. Because our collaboration among partners grew strong enough to diffuse resistance, Georgia adopted this change despite active opposition from those who had benefited most from the old system.

In Brazil, in our conception of a continuous process of research to policy, all sectors of society may pose questions, contribute to data collection, question methods and results, and insist that sound findings guide policy and practice—and future research. But the established scientific research community has insisted that our approach “was not research”. While our own methods must be open to peer scrutiny, we are concerned that arguments about the boundaries of research are likely to confuse the public rather than to engage them in research intended to improve their lives.

It is inevitable that some of our more inclusive approaches will be viewed skeptically by colleagues within the research community and by some research donors. Part of the skepticism arises from the measures by which society will judge our contributions. We applaud advancing the frontiers of science for health. Methods to judge successes in academic and economic institutions (e.g. citation indices and patents) are well established—but they are very limited. We have no similar consensus about how to evaluate research methodology for its direct and indirect contribution both to knowledge and to improved population health.

We are limited in our ability to accumulate convincing evidence about “best research practices” to achieve population health gains until we can evaluate what is working, what is not, and why. This is a task for the research community to take upon itself, with the support of policy makers who recognize the promise of the explorations we describe.

We are optimistic about the value of our experiences with alternative ways to harness resources, largely untapped in our countries, to generate and apply knowledge to improve people's health and address inequalities. On this basis, we proffer A CHALLENGE to ourselves, and all those who wish to join us to enhance the ways we do research. And we issue A CALL to our policymakers in the same spirit.



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### A CHALLENGE

*to ourselves and all those who wish to join us to enhance the ways we do research. Let us together:*

1. Open up boundaries of traditional research to include all those topics, participants, perspectives, disciplines, methods, means of dissemination and advocacy for use of results in policy and practice to improve health and health systems.
2. Accumulate our experiences and reflect on them collectively as a basis for analyzing how to do research most effectively in our settings—in pursuit of best research practices, emphasizing collective action to optimize our use of resources.
3. Develop analytic methods to evaluate how, and how much, our different approaches to research contribute to health and health systems.
4. Collaborate nationally and regionally; link to global initiatives without being driven or preempted by them.

### A CALL

*to our policymakers to:*

1. Adopt an evidence-based approach to making policy, and ensure that health service systems are equipped to use rigorous research methods to collect and analyze information from the system whereby to provide a firm foundation of evidence for future actions.
2. Look for evidence locally and regionally, and support efforts to make effective use of resources existing in our countries to create additional evidence.
3. Engage with researchers to ensure that the evidence developed is broad enough to inform and support policy makers in sectors other than health to promote policies that protect our citizens from harm and enhance their well-being.
4. Encourage inclusive, transparent, collaborative, and systematic approaches for setting priorities, allocating, and managing research—and for evaluating its contribution to health and health systems.
5. Increase public engagement in, and benefit from, collective research efforts, especially involving those whose health is most at risk, and assure that research results are publicly available to encourage open debate.
6. Assure that research support is open to all types of organizations capable of conducting good research to meet local and regional priorities, and that grants are awarded in an open, non-political, and ethical manner.
7. Invite the international community to support these efforts and to work with us to build international collaborations to synthesize and evaluate research relevance, capacity and productivity for health and development in our countries and regions—and for understanding what does and does not strengthen our capacities and systems.
8. Enlighten international institutions, academic partners in the North, and other partners to recognize the circumstances under which we conduct research, and the importance of flexible support so that our efforts can benefit from global collaboration while maintaining our own priorities and building national and regional infrastructures to implement and evaluate our own ways of doing research.



